

Neuro-oncology Service

Brain Tumours: A guide for Patients and Carers

Introduction

Each year about 7,000 people are diagnosed in the UK with a brain tumour or other central nervous system tumour. Over 300 are diagnosed at University Hospitals Coventry and Warwickshire NHS Trust.

The aim of this brief guide is to provide some information and support to patients diagnosed with brain tumours, and their families and carers. Whilst not exhaustive it may help to answer some of the important questions you may have about the diagnosis and treatment. Details of where further information can be found are given in our other leaflet **Information for You: Brain Tumours**. Please ask for a copy.

What is cancer?

Our bodies are made up of cells. Cancer is a disease of these cells. It is not a single disease with a single cause and a single kind of treatment. There are in fact 200 kinds of cancer and each has its own name and its own treatment.

Most cells in the body repair and reproduce themselves in an orderly manner. If this process becomes out of control, the cells will continue to divide and develop into a lump called a tumour.

Tumours are either **benign** or **malignant**. Doctors can tell if a tumour is benign or malignant by examining a small sample of the cells under a microscope. This is called a **biopsy**.



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Benign cells do not spread into surrounding tissue and they are therefore **not cancerous**.

A malignant tumour has cells which have the ability to spread beyond the original site. It can also destroy surrounding brain tissue and break away from the original tumour and spread to other parts of the body.

Primary brain tumours

Benign Tumours

Many primary brain tumours are benign. They do not spread to other parts of the body and if successfully removed should not cause any further problems. Some benign tumours do re-grow slowly and if this happens, treatment with radiotherapy or even further surgery may be given. Sometimes, however, it is difficult to remove the tumour because of its position within the brain or because surrounding tissue can be damaged.

Malignant tumours

There are a number of different grades of brain tumour, please ask your specialist team. These tumours are most likely to cause problems by spreading into normal brain tissue which surrounds them and causing pressure and damage to surrounding areas of the brain. These tumours rarely spread outside the brain to other parts of the body.

Secondary brain tumours

Secondary brain tumours occur when cancer cells spread from other parts of the body. They can spread from any organ, but most commonly the breast and lung.

The causes of brain tumours

The cause of most brain tumours is unknown. They cannot, however, be passed on to other people and are slightly more common in men than women.

- A small number of brain tumours occur in people who have genetic conditions such as neurofibromatosis, tuberous sclerosis or von Hippel Lindau disease.

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- People exposed to radiotherapy to the head e.g. children who have had radiotherapy for leukaemia.
- Other factors have been suggested as **possible** causes such as mobile phones, power lines and viruses.
- It is important to note that the cause of a secondary brain tumour is always a primary cancer elsewhere in the body.

Symptoms

- Headaches
- Nausea

These are usually seen in the early stages and are caused by a rise in pressure within the brain as the tumour grows. The rise in pressure is called raised intracranial pressure (ICP) and is often at its most severe in the morning. Raised intracranial pressure can also affect sight, create confusion and affect your balance.

Another common symptom is epilepsy, which can cause fits, muscle spasms and unconsciousness. A fit is a frightening experience but is not necessarily caused by a brain tumour.

How are tumours diagnosed?

Nervous system examination

This may include:

- Mental exercises, such as simple arithmetic and simple questions;
- An eye examination to see if the optic disc at the back of the eye is swollen. This is known as papilloedema;
- Hearing tests;
- Facial muscle tests;
- Tongue movement- checking the gag reflex;
- Testing the strength of arms and legs;
- Testing balance and co-ordination through walking a few steps.

MRI Scan

This uses a magnetic field to build up cross-sectional pictures of your brain. Before the test some people are given a dye into a vein to improve the pictures. You will be asked to lie still on a couch inside a long chamber.

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This can be unpleasant, especially if you don't like enclosed spaces and loud noises. As the machine is a powerful magnet you should remove any metal belongings. If you have a metal heart monitor or a pacemaker you cannot have an MRI scan.

CT Scan

This is a series of x-rays which builds up a three dimensional picture in the head. In this test you will be asked to lie with your head inside an opening in the scanner. The scan is painless but takes longer than an X-ray. It may be used to identify the exact area and size of the tumour. You may be given an injection into a vein to allow particular areas of the brain to be seen more clearly. This may make you feel hot all over for a few minutes. Before having the injection, it is important that you tell the doctor, nurse or radiographer carrying out the procedure whether you are allergic to iodine or have asthma or diabetes.

Positron Emission Tomography (PET) Scan

This type of scan provides a picture of brain activity by giving an injection of glucose attached to a tiny amount of radioactivity. The injection is given into a vein in the back of the hand. Tumours normally absorb more of the glucose and the radioactivity shows up on the scan.

A PET scan may help to tell whether a tumour is growing and whether it is cancerous (malignant) or benign. After the injection is given you will be asked to lie quietly in a dark room with your eyes closed. You will then be taken to the scanning room and asked to lie on a couch with a scanning ring around you. The dose of radiation you receive is no more than a normal x-ray. As PET scans are only available in a few hospitals you may have to travel some distance from home in order to have one.

Brain angiogram (or arteriogram)

This test shows up the structure of the blood vessels and may show up the position of the tumour within the brain. This may be useful information if an operation is planned. A small tube (catheter) is passed into an artery, often in the groin, under local or general anaesthetic. When the catheter has been passed into the right artery, a dye is injected and a series of x rays taken as the dye flows through the blood vessels.

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Electroencephalogram (EEG)

This is a recording of the electrical activity within the brain. In this, test wires are connected to small plastic discs attached to your head using a special gel. The nerve impulses are recorded on paper. It is a safe and completely painless test lasting about an hour.

Biopsy

Often it is necessary to take a small part of the tumour to find out exactly what type of tumour you have.

Craniotomy

By removing or debulking part or most of the tumour, material can be sent to the pathologist in order to obtain a diagnosis.

Please note:

The time it takes to receive the results following a biopsy/debulking/removal of a brain tumour varies from one person to another so please try to be patient. Often these only take days but in rare cases you could have to wait several weeks.

You will only receive your results when the pathologist is satisfied that an accurate diagnosis has been reached.

After brain surgery

You must not drive your car or motorcycle as the insurance is no longer valid. It is your responsibility to notify the DVLA who will make the decision of how long you must revoke your licence following the receipt of a medical report.

Types of brain tumour

Brain tumours are usually named after the types of brain cells from which they have developed.

Gliomas

These develop from the supporting cells in the brain known as glial cells. They may be named after the cell that they are made up of, or the part of the brain in which they are found, such as a brainstem glioma. More than half of all brain tumours are gliomas.

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Grading of gliomas

Grading is the term referring to the appearance of the tumour cells under the microscope. A pathologist examines the cells and looks whether they are dividing slowly or more quickly, and how abnormal they look. The grade is an indication of how quickly the tumour may develop.

Pituitary tumours

The pituitary gland produces hormones that control and regulate the other hormone producing glands in the body. They are **benign** and are called pituitary adenomas. Symptoms often include disturbances in vision or hormone levels.

Secondary brain tumours

Some types of primary cancers may spread to the brain. These are known as secondary or metastatic tumours.

Treatment of brain tumours

- Surgery
- Radiotherapy
- Chemotherapy

They may be used alone or in combination. The choice of treatment will depend on whether it is a primary or a secondary tumour. A team of doctors and other health professionals will plan your care. This is known as a multidisciplinary team and may include a neurosurgeon, a neurologist, a clinical oncologist and a Clinical Nurse Specialist.

Surgery

With most primary tumours, surgery is often the first treatment if the tumour can be removed without causing harm to surrounding brain tissue. Certain tumours, however, may not have to be operated on immediately. For example low grade gliomas are carefully monitored if they are not causing any problems. Rare tumours of the brain such as germinomas or lymphomas are sometimes treated without an operation, using radiotherapy or chemotherapy.

Surgery can range from a biopsy to a major operation where the tumour is either completely or partly removed (debulked). If a tumour has not been completely removed or there is a chance that abnormal cells may be still present following surgery, radiotherapy will usually be given after the

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operation. If surgery is not possible or necessary, radiotherapy with or without chemotherapy is used as the main treatment.

Secondary tumours

Treatment depends on the type of primary cancer it has spread from, the size and position of the secondary cancer within the brain and whether or not there are other secondary tumours elsewhere in the body.

- Steroids, such as Dexamethasone, can often control the symptoms of brain tumours. They are usually taken as tablets and are sometimes the only treatment that is needed.
- Radiotherapy, usually to the whole head, may sometimes be given to shrink and control the secondary brain tumour.
- Occasionally, if there are only one or two very small areas of secondary cancer, it may be possible to remove them with surgery or give a localised form of radiotherapy. Radiotherapy is sometimes given after an operation.
- Chemotherapy or hormonal therapy may also be helpful, depending on the type of primary cancer the tumour has spread from.

With secondary brain tumours the aim of treatment is to improve symptoms and to prolong a good quality of life. At this stage it is not usually possible to cure the cancer or to remove the tumour altogether, but the steroids, chemotherapy or hormonal therapy may extend some peoples' lives for some months.

Symptom control treatment

In both primary and secondary brain tumours, treatment for particular symptoms, such as anticonvulsants to prevent seizures and steroids to reduce inflammation and swelling around the tumours is often necessary.

Radiotherapy

Radiotherapy treats cancer cells through the use of high energy rays which destroy the cancer cells whilst doing as little harm as possible to normal cells. It is often used after surgery to treat any cancer cells that may have been left behind. It can also be given when a primary tumour cannot be removed or has come back after surgery or to treat secondary brain tumours.

Possible side effects of radiotherapy to the brain

These can be mild or more troublesome depending on the amount of radiotherapy given and the length of the treatment.

- **Tiredness:** radiotherapy often causes tiredness, so try and get as much rest as you can, especially if you have to travel a long way for treatment each day.
- **Feeling sick:** occasionally people feel nauseated but this is often treated effectively by anti-sickness drugs called antiemetics. Food may also taste different. If food cannot be tolerated it can be replaced with nutritious, high calorie drinks.
- **Headaches:** some people have headaches which can be controlled with painkillers or steroids.
- **Hair Loss:** hair is lost in the area which is being treated. This is often temporary although in some cases it may be permanent. It will depend on the dose and the length of treatment that has been given. Sometimes hair grows back within 2 to 3 months and may be a different texture and colour.
- **Skin Changes:** skin may become sore and itchy particularly in people with pale skin. This normally happens after 3-4 weeks. People with darker skin may find that it becomes darker and can have a blue or black tinge. The reaction depends on the area being treated and the individual person's skin. Some people have no problems at all, but if the skin is sensitive it is best not to overexpose it to the sun or cold winds.
- **Drowsiness:** this side effect occurs 6-12 weeks after radiotherapy. You may find that you slow down and have little energy and cannot be bothered to do much. It does gradually get better but can last up to six months.

Chemotherapy

This is the use of special anti-cancer (cytotoxic) drugs which work by disrupting the growth of cancer cells. Chemotherapy is not used for all brain tumours. It may be used alone or together with radiotherapy in people with primary brain tumours that cannot be removed with surgery.

There are different types of chemotherapy to treat brain tumours. Some are given as tablets or capsules and some are given as injections into the vein. Treatment is usually as an outpatient.

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Sometimes, during surgery to remove a glioma, biodegradable wafers containing a chemotherapy drug are put into the area of the tumour.

Side effects

Chemotherapy can cause side effects which are unpleasant although many patients do tolerate treatment well, with few side effects.

- **Lowered resistance to infection:** whilst the drug is in the body there is a temporary reduction in the number of white blood cells. When these cells are reduced, infections are more likely and tiredness is more common. During chemotherapy your blood will be tested regularly and if necessary antibiotics can be given to treat infection. If your temperature goes above 38 degrees Celsius or you suddenly feel unwell, the GP or oncology ward should be contacted straight away.
- **Anaemia:** if the number of red blood cells becomes low you will become very tired and lethargic as well as breathless. If you become very breathless you may require a transfusion.
- **Bruising and bleeding:** platelets are a type of cell that helps to clot the blood. If the number of platelets is very low you will bruise very easily and may bleed heavily from minor cuts and grazes.
- **Sickness:** some chemotherapy drugs may make you feel nauseous and can make you sick. There are now many effective antiemetics that can greatly reduce nausea and vomiting.
- **Hair loss:** this is not a common problem with drugs used to treat brain tumours, but some may cause hair thinning.

Some people can lead a fairly normal life, although many others find that they become tired easily and find the side effects difficult to bear. It is essential therefore that you do not over tire yourself.

After treatment

You will continue to have regular checkups and further scans. These will continue for several years.

If you notice any new symptoms in between these times your doctor should be informed as soon as possible.

Patient Information

For a list of sources of further information on brain tumours, please ask your Clinical Nurse Specialist for the leaflet **Information for You: Brain Tumours**. This is also available from the Macmillan Cancer Information Centre Tel 024 7696 6052 in the main entrance of the hospital.

Macmillan Neuro-oncology Clinical Nurse Specialists: Tel 024 7696 5326.

The Trust has access to interpreting and translation services. If you need this information in another language or format please contact 024 7696 5205 and we will do our best to meet your needs.

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